

The way we die now: a personal reflection

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INTRODUCTION: WHY ME?

My book, *The Way We Die Now*, was published in May 2016.¹ Since then, the most common question I have been asked is: why is a gastroenterologist writing about death and dying? I work as a gastroenterologist and general physician in a large Irish teaching hospital. Like most physicians doing general medical 'take', the majority of patients admitted under my care are frail elderly people with multiple comorbidities. And like most gastroenterologists nowadays, the majority of my speciality in-patients are people with chronic liver disease. Death is a common outcome in both groups of patients. I became increasingly aware that some families harboured unrealistic expectations of the hospital treatment of their sick elderly relatives. I also became concerned that my patients with chronic liver disease – which has a worse prognosis than most cancers – were not generally aware of this prognosis, and were not availing of proper palliative care at the end of life. I have witnessed many deaths from liver failure in relatively young people, yet death is rarely discussed with these patients and their families, who tend to assume that modern medicine can fix broken organs, or if they cannot be fixed, they can be replaced.

Most of what I had read about death and dying came from a palliative care perspective, yet at least half of all deaths, both in Ireland and the UK, take place in acute general hospitals, with only 4–5% dying in hospices. There seemed to be very little written about death and dying from the perspective of doctors working in a general hospital. No doubt a palliative care physician would have written a different book, but their patients are, if I may use the term, more 'packaged'. By the time hospice doctors become involved, much of the heavy lifting – in terms of altering expectation – has been done. I deal with death in many guises: from the rapid and messy death in the emergency department resuscitation room, to the slow, lingering death from liver disease on the general ward, to the high-tech death in the Intensive Care Unit. I witness the sudden deceleration in medical intensity, when we abruptly shift from full intervention, to the single room, the syringe-

driver and the chaplaincy service. Some of the deaths I see are undignified: the dying have not accepted or understood their situation, the truth denied them by well-intentioned relatives and doctors. Their death has been stolen from them. Death in modern general hospitals now has the faint whiff of an industrial accident, a failure of medical intervention.

Another reason for my growing interest in so-called 'end of life' issues was percutaneous endoscopic gastrostomy (PEG). Over a period of several years, I had become increasingly concerned that this procedure was being carried out on patients who derived no benefit from it. Eventually I reached the uncomfortable conclusion that, in many cases, this form of feeding was instituted mainly to meet the complex emotional, professional – even economic – needs of families and care-givers, rather than those of the patient. PEG, in these patients, was a technical panacea for existential problems.²

A GOOD DEATH?

Those who write and lecture about death and dying hold up the 'good death' and 'death with dignity' as their ideal. I am not even sure what these overused phrases mean. The ideal of a 'good death' is endlessly debated as something desirable and achievable, yet this notion is hugely subjective, poorly understood, and quite probably not a generalisable concept. I support their desire to treat pain properly and to protect the dying from futile treatments. But I wonder if what they want is to 'tame' death, to strip it of its grandeur, to turn it into a medical process that can be managed, policed and workshopped. Henry James called it 'the distinguished thing', but death, for most people, is banal, anticlimactic. The End is robbed of its significance by our new hospital rituals. Most people who die in hospitals do so after several days of syringe-driver-induced oblivion.

Ivan Illich, that turbulent priest and philosopher, argued that dying was yet another aspect of human life which had been colonised and taken over by medical busybodies.³ This medicalisation, he argued, 'constitutes

a prolific bureaucratic program based on the denial of each man's need to deal with pain, sickness and death.' This medicalisation is a form of 'cultural iatrogenesis', which caused us to lose our ability to accept death, and to devalue our traditional rituals around death and dying: 'Through the medicalization of death, health care has become a monolithic world religion.'⁴ Illich believed there is a profound difference between pain and suffering. Pain, he argued, is a *sensation*, but suffering is a *practice*: cultural iatrogenesis has robbed people in Western countries of the ability to suffer. Medicine, which convinced people that all pain is curable, has made pain unendurable: 'I invite all to shift their gaze, their thoughts, from worrying about health care to cultivating the art of living. And today, with equal importance, to the art of suffering, the art of dying.'

So what is 'a good death'? Naturally, we want it to be free of pain. Most of us want it to happen at home, in an atmosphere of dignity and calm, surrounded by family. Our contemporary culture values the idea of death as 'personal growth', a spiritual event. A 'good death' is also one where the dying man and his family and friends openly acknowledge its imminence. Death is a time, too, for 'closure', when conflicts and unfinished business are resolved. So the contemporary consensus is that it should go something like this: aged 100, after a lifetime of professional achievement and personal happiness, you become acutely ill, having never experienced any sickness more serious than a cold. This illness does not rob you of your mental faculties, your ability to communicate or to enjoy food. The nature of this illness allows your doctor to predict with pinpoint accuracy the hour of your demise. You gather your family and friends to tell them how much you've enjoyed your life, and how much you love them all. You make practical arrangements for your property and business interests. If you are religious, you receive the last rites and make peace with your God. You are able to distil and pass on the wisdom accrued over your long life. You eat one last, delicious, meal. You raise your hand and say 'Goodbye'. You close your eyes, and die immediately. Your family and friends, although distraught by your leaving, undergo a powerful spiritual experience. Your life and example has enriched their lives. Your funeral is an occasion of joy and renewal, attended by thousands. You will live forever in the memory of those you have left behind.

We know, of course, that dying isn't like this at all. Most people die after a long, chronic illness. Death is most likely to happen in a general hospital or a nursing home. It is much less likely to happen at home, and even less likely to take place in a hospice. Many dying people do not know they are at the end of life: an audit of deaths in England in 2014 found that less than half knew they were dying.⁵ Dying people commonly spend their last days unconscious, sedated and pain-free.

This fantasy described above is at least partly fuelled by the modern gospel that is the 'compression of morbidity'. This concept was popularised by James F. Fries, a Professor of Medicine at Stanford, who first wrote about his theory in 1980.⁶ Put simply, the 'compression of morbidity' teaches that as longevity increases, old age will be a period – increasingly longer – of active life and good health, ending with a short, relatively painless, final illness. American baby-boomers, bombarded with images of jogging octogenarians, have invested heavily in this concept and are desperate for it to be true. Unfortunately, it isn't: in a 2010 review of trends in mortality and disability in the USA, Crimmins and Beltrán-Sánchez concluded:

The compression of morbidity is a compelling idea. People aspire to live out their lives in good health and to die a good death without suffering, disease, and loss of functioning. However, compression of morbidity may be as illusory as immortality. We do not appear to be moving to a world where we die without experiencing disease, functioning loss, and disability.⁷

A HESITATION TO BE BRAVE

Much of the behaviour of people around the dying is characterised by sentimentality and evasion. This can take many forms: at its simplest, there are the relatives who conceal from the dying person the fact that he or she is dying. Then there are those – relatives, friends and doctors – who encourage a deluded optimism about the benefits of medical treatment, with the intention of maintaining hope. Some dying people inhabit a world of histrionic pretence. David Rieff's memoir about the death of his mother, the writer Susan Sontag, *Swimming in a Sea of Death*, is a vivid depiction of such a world.⁸

Kieran Sweeney, a GP and academic, was diagnosed with mesothelioma in 2009. He wrote about his experience as a cancer patient in the *British Medical Journal*:

Where one meets the most senior clinical staff, one is left with a sense of technical competence, undermined, with some notable exceptions, by a hesitation to be brave. Eye contact is avoided when one strays off the clinical map on to the metaphysical territory – I am a man devoid of hope – and circumlocution displaces a compassionate exploration of my worst fears.⁹

Atul Gawande too, observed that doctors shy away from what he called 'The Difficult Conversation':

Patients die only once. They have no experience to draw on. They need doctors and nurses willing to have the hard discussions and say what they have seen, who will help people prepare for what is to come – and to escape a warehoused oblivion that few really want.¹⁰

Why the 'hesitation to be brave'? Doctors increasingly see themselves as service-providers, a role that does not encourage Difficult Conversations. Consumerism, fear of litigation and over-regulation have conspired to create the customer-friendly doctor, who emerged when the doctor-patient relationship was recast in a quasi-commercial mould. It is easier, in the middle of a busy clinic, to order another scan than to have the Difficult Conversation.

Kieran Sweeney's acceptance of his situation is the exception, not the rule. He was both advantaged and disadvantaged when he was given the diagnosis of mesothelioma. As a doctor, he knew immediately what the future held in store, but this knowledge precluded all hope. Many of my patients lack the educational background or knowledge to fully absorb a diagnosis of something like mesothelioma. Apart from this 'cognitive' aspect, many simply do not want to know the grisly details about survival statistics. It is not only relatives who wish to have the truth concealed: many patients do not want to have the Difficult Conversation. The entire culture of the modern acute general hospital makes this dialogue difficult: the temptation to opt for the quiet life, to avoid the Difficult Conversation is sometimes overwhelming. Sherwin Nuland, the surgeon and writer, bitterly regretted his failure to be honest with his own brother when he was diagnosed with advanced colon cancer:

With this burden on my shoulders, I made a series of mistakes. That I made them with what seemed like the best of intentions does not mitigate how I feel about them in retrospect...I could not deny him a hope that he seemed to need.¹¹

STAFFORD HOSPITAL

The modern acute general hospital, where at least half of us are fated to end our days, is ill equipped to meet the needs of the dying. The culture, the ambience, the tone, is of haste, bustle, frayed tempers and a strange kind of giddiness. These hospitals are plagued and fettered by bogus notions of egalitarianism, which ultimately does a disservice to patients. The overwhelming impression from the various reports into the Stafford Hospital scandal was that nobody was in charge. In total, there were five official investigations into care at Stafford, culminating in the second Francis report (2013),¹² a document of some 783,710 words – slightly longer than the King James Bible (783,137 words). These reports gave some insight into how care at the hospital got to be so bad. Staff numbers had been cut so the Trust could meet financial targets, which would enable it to achieve Foundation Trust status. There were not enough Coronary Care, Intensive Care and High Dependency beds. Relations between managers and consultants were poor. Junior doctors were routinely diverted from dealing with ward patients to

the Emergency Department so that the hospital would not be in breach of a four-hour target. The politicians who expressed their shock and outrage over Stafford in parliament and in the media were often the very same politicians who had imposed this target culture on the NHS.

The witness statements to the Francis Inquiry reminded me of George Orwell's essay *How the Poor Die*, an account of his hospitalisation in Paris with pneumonia. Orwell had never been in a public hospital before, and his essay described the daily horrors of such a place: 'A hospital is a place of filth, torture and death, a sort of antechamber to the tomb.'¹³

Although there was an understandable public outcry over these accounts of casual cruelty and neglect, what the media and politicians focused on was the concept of 'avoidable deaths'. Using the Hospital Standardized Mortality Ratio (HSMR), developed by the Dr Foster Intelligence Unit at the School of Public Health at Imperial College London, it was estimated that Stafford Hospital had a higher than average mortality rate. In February 2013, the *Guardian* reported: 'An estimated 400–1,200 patients died as a result of poor care over the 50 months between January 2005 and March 2009 at Stafford Hospital.'¹⁴ In June 2013, the *Daily Telegraph* reported: 'A review of deaths at Mid-Staffordshire NHS Foundation Trust by police and other officials has identified hundreds of cases between 2005 and 2009 where poor care could have led to deaths.'¹⁵

Many questioned the HSMR statistical methodology. Paul Taylor, an expert in health informatics, wrote an illuminating essay called *Rigging the Death Rate*.¹⁶ Taylor and several others demonstrated the crudity of this ratio. It is subject to many biases and distortions, such as the accuracy of coding, the quality of local GP care, and access to hospices. A commercial competitor of Dr Foster Intelligence, Caspe Healthcare Knowledge Systems, was hired by another hospital – Medway – which also had a high HSMR. They advised the Trust it had been under-using the specific code for palliative care: by increasing the proportion of patients it coded as receiving palliative care, Medway lowered its HSMR dramatically. The first Francis Inquiry commissioned an independent assessment of the HSMR statistical method by the epidemiologists Professor Richard Lilford and Dr MA Mohammed, who concluded that 'the methodology used to derive the Dr Foster SMR is riddled with the constant risk-adjustment fallacy and so is not fit for purpose.'¹⁷ Although the various public inquiries into Stafford Hospital were covered in some detail by the press, it was less widely reported that Dr Mike Laker of Newcastle University was asked by the Mid Staffordshire Trust to examine a number of cases where families felt that poor care had contributed to a relative's death. He interviewed 120 families and

examined 50 case notes, and concluded that poor care caused death in 'perhaps one'.¹⁸

Robert Francis stated that no firm conclusions could be drawn from the hospital mortality figures. He acknowledged that unkindness, rather than a high death rate, was the main concern of those who had given evidence: 'It was striking how many accounts I received related to basic elements of care and the quality of the patient experience, as opposed to concerns about clinical errors leading to death or injury.' Despite this, the perception persists among the public, media and politicians that any deaths above the national average must be the consequence of poor care, and therefore avoidable. Stafford has thus fixed an idea in the public consciousness of hospital death as a failure of medical care. The scandal also strengthened the prevailing societal view that doctors and nurses must be more 'accountable'. In Britain there are dozens of agencies, colleges and quangos charged with overseeing those who work in hospitals. The moral philosopher Onora O'Neill addressed this accountability culture in her Reith Lectures in 2002, and observed that while in theory the new regulations make professionals more accountable, in practice they achieve little, except an increase in suspicion: 'currently fashionable methods of accountability damage rather than repair trust.'¹⁹

THE LIVERPOOL CARE PATHWAY

The Liverpool Care Pathway (LCP) was scrapped mainly because of sensationalist media coverage. Genuine concerns about a small minority of patients inappropriately put on the Pathway were cynically seized on by the press, who accused hospitals and doctors of carrying out involuntary euthanasia, incentivised by cash bonuses. (In the target-driven NHS, hospitals were actually given bonuses for reaching specific targets on palliative care; one such target was the percentage of dying patients placed on the LCP.) An independent inquiry, chaired by Baroness Julia Neuberger, produced a report called *More Care, Less Pathway*.²⁰ The report concluded that when the Pathway was operated by well-trained and well-resourced clinical teams, it worked well. Where care was already poor, the LCP had been used as a tick-box exercise. Neuberger observed that the word 'pathway' is misleading, as it suggests a road going somewhere. She sensibly suggested dropping the word 'pathway' in favour of the more neutral term 'end of life care plan'. Rather bravely, Neuberger concluded that if we don't have a proper national conversation about dying, doctors and nurses will become 'the whipping boys for an inadequate understanding of how we face out final days.'

The relatively few failures of the Pathway had fatally contaminated the 'brand' in the mind of the public. Why did it fail? Most people nowadays die after a long illness.

It can be difficult, therefore, to be sure when a patient has moved from having a chronic illness to dying. Some patients were probably put on the Pathway too early; others should never have been put on the Pathway at all. The vast majority of patients, however, were put on the Pathway correctly, and had an easier death because of it. Poor communication was at the root of virtually all complaints about the LCP. The tick-boxy forms gave the impression of a one-size-fits-all exercise: the mistake was to prescribe for populations, not individuals.

The story of the LCP shows the difficulties faced by doctors working in acute general hospitals. We are simultaneously accused of being both too interventionist and aggressive in our treatment of the dying, and also too hasty in putting patients on a palliative pathway and the syringe-driver. The media – particularly newspapers – managed to reduce a difficult and complex debate to shouty, hysterical headlines. Acute hospitals are criticised, with some justification, for failing to care properly for the dying, yet society has handed over most of the responsibility for care of the dying to these very same hospitals. Nursing homes commonly send dying patients into emergency departments, because it is much easier for them, administratively and legally, if the patient dies in hospital. In my own hospital, 11 patients referred from nursing homes died within 30 minutes of arrival to the Emergency Department during a single month in 2015.

Society has thrust onto these hospitals the messy, intractable and insoluble aspects of life, such as old age and death. Ivan Illich assumed that 'medicalisation' is something doctors actively seek, to enhance their power. But he was wrong. Medicalisation does not empower doctors: they suffer.²¹

CANCER

Cancer inspires more fears and fantasies than any other cause of disease and death. In *The Way We Die Now*, I wrote about the experience of famous cancer sufferers, including Christopher Hitchens, Susan Sontag and Nuala O'Faolain. Another famous victim was Josephine Hart, the novelist and wife of Maurice Saatchi, the advertising guru and former chairman of the Conservative Party. Hart died a year after being diagnosed with a rare primary peritoneal carcinoma. Saatchi was appalled by her treatment, which he described as 'medieval, degrading and ineffective.' He declared war on cancer: 'I intend to cure cancer; you see. I mean to do it. I expect to do it.'²² Saatchi proposed a private member's Bill, the Medical Innovation Bill, in the House of Lords in 2013, with the intention of giving doctors the freedom to treat cancer patients with 'cutting edge' and 'revolutionary' treatments, without the fear of litigation. Although Saatchi's public relations campaign was slick and influential, informed opinion (the BMA, the Royal

Colleges) saw no need for such legislation. More than 100 oncologists wrote to *The Times* opposing the Bill: 'We are concerned that rather than promoting responsible scientific innovation in the treatment of cancer, the Medical Innovation Bill will actually encourage irresponsible experimentation producing nothing more than anecdotal "evidence", at the potential expense of causing serious harm and suffering to patients.' *The Lancet Oncology* devoted an editorial to the Bill, concluding that it 'strikes at the heart of evidence-based medicine.'²³ One of the last decisions taken by Norman Lamb, junior Health Minister in the Conservative/ Liberal Democrat coalition government, was to veto the Bill in the House of Commons.

Cancer treatment seems to offer some patients a toxic combination of false hopes and a bad death. Even those within oncology accept that the current model of cancer care in developed countries has become unaffordable and unsustainable. The Lancet Oncology Commission produced a lengthy report in 2011 called *Delivering Affordable Cancer Care in High-income Countries*.²⁴ The Commission concluded that cancer care is in crisis, driven by overuse and futility, and that 'the medical profession and the health-care industry have created unrealistic expectations of arrest of disease and death. This set of expectations allows inappropriate application of relatively ineffective therapies, including surgery, in the name of care. In developed countries, cancer treatment is becoming a culture of excess.'

Even the language of cancer is different: people afflicted with the condition are expected to 'fight' it; if and when they die, they are said to have 'lost their battle'. Christopher Hitchens observed in his cancer memoir, *Mortality*:

People don't have cancer: they are reported to be battling cancer. No well-wisher omits the combative image. You can beat this. It's even in obituaries for cancer losers, as if one might reasonably say of someone that they died after a long and brave struggle with mortality. You don't hear it about long-term sufferers from heart disease or kidney failure.²⁵

One of the root causes of this crisis in cancer care is sentimentality. I am often told by well-meaning family members that their stricken relative is a 'fighter', by which they mean that the known biological statistics appropriate to other, lesser souls, do not apply in this particular case. Lance Armstrong persuaded many cancer sufferers, including the singularly unsparty Susan Sontag, that cancer could be 'beaten' by sheer force of will. The American science writer George Johnson observed of this sentimentality in *The Cancer Chronicles*:

Now there is a cancer culture, and whether you had a harmless in-situ carcinoma removed with a simple lumpectomy or are fighting the terminal stages of metastatic melanoma, you are called a survivor. In

the first case there was nothing to survive. In the second case there will be no survival.²⁶

The Irish Cancer Society has launched an 'ambitious new strategy statement' for 2013 to 2017 entitled *Towards a Future without Cancer*. They modestly concede that 'this may not be achieved in the lifetime of the strategy statement'.²⁷ Cancer Research UK's current campaign proclaims: 'We will beat cancer.'

DO NOT RESUSCITATE

In February 2011, Janet Tracey, aged 63, was diagnosed with metastatic lung cancer. Two weeks later, she was involved in a road traffic accident and sustained serious injuries, including a fractured cervical spine. She was taken to Addenbrooke's Hospital in Cambridge, where she was admitted to the ICU. In a paper published in 2014, Fritz et al. summarised the subsequent events:²⁸

She had metastatic lung cancer and chronic lung disease with an estimated prognosis of 9 months. She was intubated and ventilated, and had two failed extubations. The family were informed that, if the third extubation failed, Mrs Tracey would be 'allowed to slip away', but there was no documentation of a discussion with Mrs Tracey.

A DNACPR form was written, and Mrs Tracey was successfully extubated and moved to the ward. The family subsequently discovered the DNACPR form and asked that it be removed, which was done. Unfortunately, Mrs Tracey deteriorated further and, after discussions with the family (Mrs Tracey was clear at this point that she did not want to discuss resuscitation herself), a second DNACPR form was completed. Mrs Tracey died on 7 March 2011 without attempted CPR.

The family subsequently instituted legal proceedings against the hospital, alleging that Mrs Tracey had two DNACPR orders imposed on her without being informed or consulted. The doctors at Addenbrooke's insisted they had discussed this matter with both the patient and her family. However, because this discussion was not documented in the hospital notes, the High Court Judge Nicola Davies ruled that this conversation had not taken place. Judge Davies, however, declined to hear legal arguments about a breach of human rights, and the family took their case to the Court of Appeal in 2014. Lord Dyson, the Master of the Rolls, said: 'since a DNACPR decision is one which will potentially deprive the patient of a life-saving treatment, there should be a presumption in favour of patient involvement. There needs to be convincing reasons not to involve the patient.'

The Tracey judgment will, I believe, have a profound effect on medical practice. Stories about DNACPR

orders had been appearing regularly in the press even before the Tracey ruling. The usual theme of these stories was of families finding out that their elderly relatives had been subject to a DNACPR order without their knowledge, with the implication that this was a form of back-door euthanasia. These stories fed the same hysteria that led to the end of the Liverpool Care Pathway. Will the Tracey ruling result in more dying people undergoing futile and undignified CPR as their last experience?

HOW DOCTORS DIE

In a chapter entitled *To Philosophize is to Learn How to Die*,¹ I looked at the deaths of famous philosophers and novelists (such as Tolstoy and Maugham) who had written about death. My rather banal conclusion was that some philosophers die well, some badly; they appear to have no particular advantage over non-philosophers: the claim that philosophy prepares one to meet death with equanimity appears to be unfounded. Doctors, however, might have the edge over philosophers in this regard. A 2003 study from Johns Hopkins University²⁹ examined doctors' preferences for their own care at the end of life. Most had an advance directive. The overwhelming majority did not want CPR, mechanical ventilation or PEG feeding. Other studies have confirmed this preference. An American doctor, Ken Murray, wrote an article called *How Doctors Die* in 2011:

It's not a frequent topic of discussion, but doctors die, too. And they don't die like the rest of us. What's unusual about them is not how much treatment they get compared to most Americans, but how little. For all the time they spend fending off the deaths of others, they tend to be fairly serene when faced with death themselves. They know exactly what is going to happen, they know the choices, and they generally have access to any sort of medical care they could want. But they go gently.³⁰

The uncomfortable conclusion is that doctors routinely subject their patients to treatments they wouldn't dream of having themselves. This does not surprise me. I have often asked my colleagues, when lecturing on the subject of PEG tubes, whether they would ever agree to having this procedure performed on themselves: the answer is usually a near-unanimous 'No'.

CONCLUSION: WE CAN'T PRESCRIBE A 'GOOD DEATH'

Every month seems to arrive with yet another well-meaning report on end-of-life care. These documents are all based on the unspoken assumption that death can somehow be sanitised and standardised. There is a perception – even a consensus – that death is something that medicine should somehow 'sort out', that a 'good death' is something that doctors should be able to prescribe, as we might prescribe a course of antibiotics. But our needs are spiritual, not medical. Medicine's dominion should be limited and explicitly defined. Medicine, and our culture, would be happier and healthier if we stopped expecting it to solve our existential problems, if we stopped thinking of our bodies as machines, and if we gave up our fantasies of control and immortality.

As contemporary issues, assisted suicide and advance directives are both a symptom of a deeper malaise (namely, the obsession with control) and a distraction. They are a distraction because the real issues are elsewhere. Our sense of common decency – of kindness – has become sclerosed. Kindness was the ingredient most lacking in the care of patients at Stafford. Can common decency be regenerated by regulation and government diktat? We have witnessed, to our cost, the poisonous effects of targets, and the paradox that more regulation of professionals leads only to increased suspicion, rather than greater accountability.

We cannot, like misers, hoard health; living uses it up. Nor should we lose it like spendthrifts. Health, like money, is not an end in itself; like money, it is a prerequisite for a decent, fulfilling life. The obsessive pursuit of health is a form of consumerism, and impoverishes us. Medicine should abandon its quest to conquer nature, and revert to its traditional roles of providing comfort and succour, and accompanying the dying: the doctor as *amicus mortis*. We are frail and vulnerable animals, yet we have come to believe that everything that happens to us – including death – is our fault, our doing, our responsibility. Human agency has replaced the power of nature, in Freud's words, 'majestic, cruel and inexorable.'

REFERENCES

- 1 O'Mahony S. *The Way We Die Now*. London: Head of Zeus; 2016.
- 2 O'Mahony S. Percutaneous Endoscopic Gastrostomy (PEG): cui bono? *Frontline Gastroenterol* 2015; 6: 298–300. <http://dx.doi.org/10.1136/flgastro-2014-100521>
- 3 O'Mahony S. Medical Nemesis 40 years on: the enduring legacy of Ivan Illich. *J R Coll Physicians Edinb* 2016; 46: 134–9. <http://dx.doi.org/10.4997/JRCPE.2016.214>
- 4 Illich I. *Limits to Medicine: Medical Nemesis*. London: Penguin; 1976.
- 5 Royal College of Physicians, Marie Curie Cancer Care. *National care of the dying audit for hospitals, England*. National report. London: Royal College of Physicians, 2014. <https://www.rcplondon.ac.uk/projects/outputs/national-care-dying-audit-hospitals> (accessed 7/11/16).
- 6 Fries JF. Aging, natural death, and the compression of morbidity. *N Engl J Med* 1980; 303: 1369–70. <http://dx.doi.org/10.1056/NEJM198012043032317>
- 7 Crimmins EM, Beltrán-Sánchez. Mortality and morbidity trends: is there compression of morbidity? *J Gerontol B Psychol Sci Soc Sci* 2010; 66: 75–86. <http://dx.doi.org/10.1093/geronb/gbq088>
- 8 Rieff D. *Swimming in a Sea of Death: A Son's Memoir*. London: Granta Books; 2008.
- 9 Sweeney K, Toy L, Cornwell J. A patient's journey: mesothelioma. *BMJ* 2009; 339: b2862. <http://dx.doi.org/10.1136/bmj.b2862>
- 10 Gawande A. *Being Mortal: Illness, Medicine, and What Matters in the End*. London: Profile Books; 2014.
- 11 Nuland SB. *How We Die*. New York: Alfred A. Knopf; 1994.
- 12 Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry; 2013. <http://www.midstaffpublicinquiry.com> (accessed 7/11/16).
- 13 Orwell, G. How the Poor Die. In: *Decline of the English Murder and Other Essays*. London: Penguin; 1965.
- 14 Campbell D. Mid Staffs hospital scandal: the essential guide. *Guardian* 6 February 2013. <https://www.theguardian.com/society/2013/feb/06/mid-staffs-hospital-scandal-guide> (accessed 7/11/16).
- 15 Dominiczak P. Mid-Staffs: Police investigating up to 300 deaths. *Daily Telegraph* 10 June 2013. <http://www.telegraph.co.uk/news/health/10111192/Mid-Staffs-Police-investigating-up-to-300-deaths.html> (accessed 7/11/16).
- 16 Taylor P. Rigging the Death Rate. *London Review of Books* 2013; 35(7): 12–5. <http://www.lrb.co.uk/v35/n07/paul-taylor/rigging-the-death-rate> (accessed 7/11/16).
- 17 Mohammed MA, Lilford R, Rudge G et al. The findings of the Mid-Staffordshire Inquiry do not uphold the use of hospital standardized mortality ratios as a screening test for 'bad' hospitals. *QJM* 2013; 106: 849–54. <http://dx.doi.org/10.1093/qjmed/hct101>
- 18 Department of Health. *Robert Francis Inquiry into Mid-Staffordshire NHS Foundation Trust*. London: Department of Health; 2010. http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113018 (accessed 7/11/16).
- 19 O'Neill O. *A Question of Trust*. Cambridge: Cambridge University Press; 2002.
- 20 Department of Health. *More Care, Less Pathway. A Review of the Liverpool Care Pathway*. London: Department of Health, 2013. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf (accessed 7/11/16).
- 21 Leibovici L, Lièvre M. Medicalisation: peering from inside medicine. *BMJ* 2002; 324: 866.
- 22 Grice E. 'I was a desperate lover trying to save his love.' *Daily Telegraph* 28 April 2013. <http://www.telegraph.co.uk/news/health/10024231/I-was-a-desperate-lover-trying-to-save-his-love.html> (accessed 7/11/16).
- 23 Editorial. Undermining the Hippocratic Oath: the Medical Innovation Bill. *Lancet Oncol* 2015; 16: 1. [http://dx.doi.org/10.1016/S1470-2045\(14\)71139-8](http://dx.doi.org/10.1016/S1470-2045(14)71139-8)
- 24 Sullivan R, Peppercorn J, Sikora K et al. Delivering affordable cancer care in high-income countries. *Lancet Oncol* 2011; 12: 933–80. [http://dx.doi.org/10.1016/S1470-2045\(11\)70141-3](http://dx.doi.org/10.1016/S1470-2045(11)70141-3)
- 25 Hitchens C. *Mortality*. London: Atlantic Books; 2012.
- 26 Johnson G. *The Cancer Chronicles: Unlocking Medicine's Deepest Mystery*. London: The Bodley Head; 2013.
- 27 Irish Cancer Society. *Towards a future without cancer*. Dublin: The Irish Cancer Society, 2013. https://www.cancer.ie/sites/default/files/content-attachments/irish_cancer_society_strategy_statement_2013-2017.pdf (accessed 7/11/16).
- 28 Fritz Z, Cork N, Dodd A et al. DNACPR decisions: challenging and changing practice in the wake of the Tracey judgment. *Clin Med* 2014; 14: 571–6. <http://dx.doi.org/10.7861/clinmedicine.14-6-571>
- 29 Gallo JJ, Straton JB, Klag MJ et al. What do physicians want and do they express their wishes to others? *J Am Geriatr Soc* 2003; 51: 961–9.
- 30 Murray K. *How Doctors Die*. 30 November 2011. <http://www.zocalopublicsquare.org/2011/11/30/how-doctors-die/ideas/nexus> (accessed 7/11/16).